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From a 'care-free' distance? Adult sons about their parents with dementia: A cross-cultural enquiry

Martina Zimmermann

1. Introduction

How do adult sons perceive of themselves as they confront their parent's older age and memory loss? In an earlier work I introduced the concept of care-free distance in the context of adult sons writing about their parent with dementia (Zimmermann 2017, 49–73). By this concept I meant that adult sons would be able to write from a position less affected by the burdens and pressures of the actual caring experience, which would influence how they represent their mother or father.¹ This chapter wants to interrogate this care-free notion with a view to unpicking how dealing with an ageing parent impinges on the son's identity and self. I will not directly focus on responsibilities of care here, given that gender does not necessarily determine how caring is perceived differently (Sharma, Chakrabarti and Grover 2016). Rather, I take the caring role of the adult son as their connector to ageing – confronting them with their own ageing and potential memory loss as they navigate, in their own midlife, care for their parents.

Ageing has long been considered 'antithetical' to hegemonic masculinity – a concept that includes the following themes: (1) concealing emotions, (2) being

¹ I had made this claim in the awareness that, in comparison to adult daughters, adult sons often continue to be less involved in the active care of their parent. But already at the time I cautioned that, according to a series of sociological studies, since the 1990s men have increasingly become involved in caring, approaching female levels (Zimmermann 2017, 26).

the breadwinner and being admired and respected, and (3) projecting an air of toughness, confidence and self-reliance (Springer and Mouzon 2019, 200, 186). I will use these themes to think through how adult sons cope with an ageing parent and their memory troubles. How do they deal with emotions; what role does their professional status play in how they write and, linked to this, how is their self-reliance projected? Taking into account that identity perception also depends on the cultural context and the carer's demographics, including age, education and ethnicity (Sharma, Chakrabarti and Grover 2016; Springer and Mouzon 2019), I will take a cross-cultural approach, looking at the accounts of three adult sons in Italy, Britain, and the United States.²

Michele Farina's *Quando andiamo a casa? Mia madre e il mio viaggio per comprendere l'Alzheimer. Un ricordo alla volta* ('When are we going home? My mother and my journey to understand Alzheimer's. One memory at a time' 2015) offers a journalistic account of experiences with dementia in Italy. In writing a documentary, Farina can adopt a distanced reporting style; concurrently, his narrative reveals itself as a gradual rapprochement with his own fears of succumbing to dementia after his mother's death. *Take Me Home: Parkinson's, My Father, Myself* (2007) by English writer Jonathan Taylor explores relational aspects of identity further. Taylor's search for his father's past becomes equivalent to the search for his own identity, given that Taylor is no longer recognized by his father with dementia. How much does the choice of narrative form in these accounts depend on the parent's memory loss or on the son's profession? And how does cultural tradition direct concepts of health in old age? I address these questions by reading the above two texts against *A Necessary End* (1994) by American writer and journalist Nick Taylor, who traces the ageing and dying of his mother (from vascular dementia) and father (from heart disease) against their continued desire for self-determination.

While Farina's text appears to emphasize the public debate of dementia in Italy, the accounts by Jonathan Taylor and Nick Taylor seem to be much more private engagements with their parents' illness. I look at them here together to acknowledge that illness narratives come in many forms and genres (Bolaki 2016). More so, the distinct genre chosen by Farina particularly speaks to the

² References from all three narratives are incorporated in brackets in the running text; translations from the Italian original are my own.

challenge of negotiating one's own mortality as an ageing man. Considering a range of conditions typical in older age, including Alzheimer's, Parkinson's, stroke and heart disease, this chapter explores concepts of independence, autonomy and health as central to identity and self within and beyond the framework of hegemonic masculinity.

2. Michele Farina: Borrowing the pain of others

Michele Farina, whose mother had shown first symptoms of dementia in 1994, publishes a documentary about his 'journey to understand Alzheimer's'; a journey through the 'Italy of the dementias' (25) that takes him through his mother's illness experience again. In over two years of travelling, beginning eight years after the mother's death, he 'collected stories, anger, tears, surprises, laughter' (24). In recounting these, *Quando andiamo a casa?* tackles 'stigma, enigma, taboo, social rejection, isolation: zero laughter' (61). It lays into a country 'in which doctors do not speak with the patients' (299). It is also a life-affirming manifesto for dementia as a multi-factorial condition that requires, to be understood and addressed properly, the perspective of many different parties: 'patients, families, healthcare workers, organisational structure, institutions, researchers, those with other conditions' (25). Farina encounters them all, writing the story of an entire nation.³ He explores the manifestations and consequences of the 'collapse of families and society to meet the growing need for care' that has long been coming for Italy, other Mediterranean countries and the Global North as a whole (Comas-d'Argemir and Soronellas 2019, 317). The impact of population changes in Italy has been of serious concern since the 1980s, when the demographics already made 'old-age politics a pressing issue' (Caviglioli 2005, 50). *Quando andiamo a casa?* traces, one decade into the twenty-first century, the impact of the inadequate political and societal response to these issues as much as the effect of what neuro-psycho-pharmacologist Marco Trabucchi chastises as 'bureaucracy and indifference' (348).

³ Italy's sharp North-South divide is less obvious in Farina's account, but possibly perceivable in the Milanese journalist's choice of scientist interlocutors, most of whom work in northern universities; but this choice might also be explained by the close research links among these medical scientists and clinicians.

The importance of Farina's work cannot be overstated, as it sharply resonates with healthcare policy and its insufficient implementation in other European nations. For example, Farina dismantles politicians across the spectrum for their ignorance as regards a 'national plan for the dementias' (252–4). Concurrently, he highlights the diagnosis-therapy-assistance trajectory successful at a local level, where 'patients and their families are accompanied every step of the way' (387). Compare this to the situation in England.⁴ The Department of Health and Social Care published plans like 'After a Diagnosis of Dementia: What to Expect from Health and Care Services' in May 2018, but local activists continue to struggle for a dementia strategy that would implement such guidance and, among other things, allocate to each individual diagnosed with dementia an empowered and trained support who has continuity of involvement throughout the course of the disease (Zimmermann and Britton 2018).

Farina's book is a prime example of life-writing whose author-narrator seeks to stay in control. Writing about a condition that apparently impacts on one's autonomy or potency comes with the necessity to find some 'compensatory power and freedom' (Couser 1997, 185; Zimmermann 2017, 101–3; 2019). *Quando andiamo a casa?* brings Farina the reward of a journalistic success that turns him into 'a good messenger' (394) and the book's reception into a platform for national activism to overcome Alzheimer's disease 'as something vague and far away, something unlikely, something exotic' (21); it is the beginning of what is meanwhile established as a national 'Alzheimer Fest' – 'a great Festival of Alzheimer's open to all related conditions' (424).⁵

At the same time, the narrative form of a documentary ensures that Farina's personal experiences and admission of fears and inadequacies can authoritatively become part of and mix with the stories of others. His scrutiny of homecare help in Italy deserves particular mention in this context, not only because it answers concerns by scholar of ageing Kathleen Woodward (2012) who laments the narrative absence from illness life-writing of the professional carer. It also is a key moment in the text where Farina's scrutiny first turns to

⁴ Healthcare politics is devolved in the United Kingdom; this means that the document discussed in this paragraph is valid for England, but not Northern Ireland, Scotland or Wales.

⁵ 'Alzheimer Fest', accessed 16 September 2020, <http://www.alzheimerfest.it/>. The festival was launched in 2017 and takes place once a year.

care for his mother. Homecare is largely left to the illegal immigrant, often of Northern African, Latin American, or Asian origin. A chapter entitled 'saintly carers' explores the 'intercontinental alliance' between carers and patients, offering the vignette of a woman from the Ivory Coast and her baby son taking care of a patient who no longer walks or talks (108). Following this emotional portrait of an elective affinity, 'a family rendered multi-ethnic by dementia' (109), Farina lets the reader glimpse into the 'cross-cultural challenge' (119) of having had the Peruvian carer Ines in their own home, including social responsibilities coming with wanting to help immigrants obtain citizenship after they had spent years as part of the nuclear family (119). Or take the following example where the form of the documentary helps Farina to distance himself from his own experience. He delivers pungent criticism against the 'infantilisation of old people [...] typical for certain care systems and their capacity to make profit, to take care of the highest possible number of old people with the minimum possible number of carers' (91). With this reference to Atul Gawande's *Being Mortal* (2014), he chastises the use of tranquilizers in institutions. But in doing so, he admits that, in the care for his mother, his family had administered "some little drops" considering it 'a form of protection, relief, not like an instrument of coercion' (92–3). Such critical reflection, Farina acknowledges, is only possible from a position of authority and closure, attained after the mother's death: 'Why am I feeling more free now? Because [my mother] is no longer there and because regrets have taken the place of fear?' (93).

Reminiscent of patient activists, Farina relies on narrative strategies that help him emotionally to distance himself from a condition that concerns the brain (Zimmermann 2017, 101; 2019). He frequently refers to the dementia brain as a furnace being turned off and taking a long time to cool down (e.g. 15–16, 45, 102), writes of his brain as a 'kilo and 300 grams of entrails and neurons, smelling of senescence' (277) and describes himself as part of the 'generation Nutella' to avoid mention of the baby boomer generation (104). These narrative tactics all have the effect of creating analytical space between the author-narrator and his outlook, emphasizing Farina's 'attempted flight' from the reality of the disease (21) during the mother's lifetime. The emotional rapprochement with his mother's condition is perhaps best documented in how Farina had not been able to deal with his mother's incontinence. Explaining

this by way of referencing Philip Roth's monumental *Patrimony* (1991) expresses Farina's speechlessness masterfully (355–7):

Patrimony, the origin of the world. I don't know whether I was able to live 'the changes' of my mother in this spirit. I don't remember. I hope so, but it is easier to think this now: faced with it, as she was alive, day after day, for years, it must have been hard. Nappies taint us, this is the truth. Or they become everyday, which is even worse.

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Patrimony is one of the most widely known and referenced illness memoirs (see also Heike Hartung's chapter in this collection). As such, it can serve Farina as a surrogate for writing about his own experience.

It becomes ever clearer that *Quando andiamo a casa?* is also Farina's attempt at coming to terms with his fears and loss. Only 'after the hard mourning,' Farina admits, he felt the need 'to rediscover [...] things that I had never tried to know (maybe because there was no cure in sight)?' (23). In his encounters with geneticists, medical scientists and practising clinicians, Farina now works through his own risk of having inherited the condition (104), and the question of how he would deal with a positive genetic test (152). Eventually, Farina acknowledges an 'inevitable reflex: to borrow the pain of others to put our own pain in perspective (ridimensionare). Even though, in this way, sometimes we end up reliving it, in real proportions; or we weld one to the other' (392). Put differently, *Quando andiamo a casa?* comes down to Farina's rapprochement with his own potential future by way of exploring his mother's dementia in the experiences of others:

Touring Italy I travelled in time: I returned to the past, I relived things I had forgotten. I had seen my mother again a thousand times, in a thousand faces. After all these years I, who during the disease had constructed a fortress and closed down loopholes to protect her and to protect myself, have been travelling putting her story onto the windscreen like a travel permit.

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The result of his journey is not only a journalistic masterpiece that unconditionally centres around individual patients and carers. It comes with the important insight that: 'I set out on this journey with nostalgia for my mother, with the feeling and the fear of having to find her again, maybe follow

her [...] I don't know how it will be, when I might be the primitive son of my son. But now I am less afraid' (422). Identity for Farina is a question of working through his past behaviour and attitudes to his mother's condition – and to do this in a form that is consistent with his profession and enables him emotionally to stay in control. For Jonathan Taylor, whose narrative I now turn to, identity is equally a question of negotiating with his behaviour in the past, but it is also a question of unpicking the relationship with his father – of discovering his father.

3. Jonathan Taylor: Rationalizing aggression

Take Me Home creates an identity as it documents its search. The book's dedication frames this undertaking as risky and inconclusive: 'to my father, John Taylor (1928?–2001), who would probably have hated it'. John Taylor's memory problems begin when Jonathan Taylor is still a teenager and, as such, they challenge him especially during his formative years with long-term impact on his identity. The challenge is twofold: his father no longer recognizes him; and, at a time when his parent can no longer offer 'his own version of events' (225), Jonathan Taylor discovers that his father might have committed "“identity fraud”" (45). *Take Me Home* is Taylor's version of events, pieced together in the need to figure out 'what our relationship would have been like if [my father] hadn't been ill' (193).

Taylor's father has Parkinson's disease with Capgras syndrome. In this condition, John Taylor takes his son for an impostor who claims to be his son. Aggravating the situation, he takes the impostor's 'real' identity to be that of a former colleague, who (so Taylor finds out after his father's death) caused his father great grief, eventually leading to his early retirement and subsequent depression (12–13). Changes in relationships are perceived of as one of the most difficult transitions families go through when a parent has been diagnosed with dementia (Roach, Drummond and Keady 2016); and dementia is seen as a 'threat to love relationships' (Krüger-Fürhoff 2015, 95). John Taylor's condition determines how the son has to live with several versions of himself (I am adapting Douwe Draaisma's ideas here): how he was as a child when his father was still well, how he is in the daily presence of his father's condition,

how he is in the mind of his father's Capgras syndrome, and all these are perhaps 'too much to be integrated in a single self' (Draaisma 2009, 438). How does Taylor cope with such a challenge to his identity?

Illness life-writing has often been described as supporting and reflecting the author-narrator's search for continuity in a life disrupted by illness. Taylor writes continuity into the relationship between patient and carer, father and son, parents and children more generally. He identifies parallels between his parents' love story and his own falling in love with his future wife (56–7); the rejection experienced at the hand of his future father-in-law for him resonates with his own father's upset, as he refers to 'pidgin Greek or Parkinsonian English, the languages [that] fail to express the love and rage of fatherhood' (63); and, perhaps most importantly, the experience of care creates continuity (19). Its all-consuming role is broached early on, in the second chapter. Entitled 'help help help', it attends to the daily minutiae of caring, listed in intervals as short as five minutes. The exclamation refers to what the father yells when he does not recognize his son and wishes to 'get *that person* away from me' (15, emphasis original). This lack of recognition dominates much of Taylor's illness experience; at least, if we can take the book cover as an extension of Taylor's impressions: printed in glossy relief, 'help help help' runs from line to line across the entire dust jacket.

But the continuity expressed in 'help help help' goes much deeper. It points to Taylor's key coping strategy, which in turn reveals much about the severity of the father's condition (Gelman and Greer 2011; Steck et al. 2007). In Capgras syndrome, particular hostility is projected onto the double, and all familiarity and warmth are removed from the relationship (Draaisma 2009, 432). Taylor is confronted with anger and aggression, including having 'the front door slammed in my face [...] meals thrown at me [...] and slaps aimed haphazardly in my direction' (213). In this way, 'help help help' is also Taylor's own plea. It is what he screams in a drunken state, beaten up by some youths (101), but not wanting 'to go home where I'm mistaken for a "him" who could be any-him' (100). With the help of alcohol and drugs, Taylor adopts a strategy of '*willed dementia*' as a teenager, actively seeking to escape his upset (161, emphasis original). This coping mechanism now challenges his search for identity.

Identity means two things at once and in dynamic exchange: 'modelling oneself *on* the other, and the establishment of the self as distinct, individual,

different *from* the other' (King 2000, 31, emphases original; see also Burke 2014). In reliance on Nicola King's definition, identity is doubly at stake in *Take Me Home*: Taylor has no clear idea of his father's past nor does he have rich positive memories of the lived relationship with him before his illness. All that remains is for Taylor to 'trace [in retrospect] the story of my father's gradual decline [...] and shape it into something meaningful' (226) – a neat summary of Taylor's book-long activities, as the memoir's near symmetric organization reflects the core business and intention of *Take Me Home*. Its two central parts cover Taylor's search for the father's own past as well as the son's happy memories of him.

In the closing part's epigraph Taylor refers to Blake Morrison's bestselling *And When Did You Last See Your Father?*, the account of a son trying to come to terms with a difficult father, a 'bullying, shaming undemocratic cheat', who also wanted 'the best for [Morrison]' (1993, 11, 132). Morrison's narrative choices bring home Taylor's emotional emergency. Morrison systematically alternates chapters of past memories with those detailing the lived experience of his father's short illness and dying in the present. Chapters exploring childhood memories are told in the present tense, in order to draw the reader into the author-narrator's remembered formative years. Taylor, by comparison, writes about the past in the past tense, admitting, in response to Morrison's question, that 'I don't know when I last saw my father "unmistakably there, in the fullness of his being, him", because I'm not sure who my father was' (261).

Taylor's efforts to answer this question go in two directions: searching out the father's past and appreciating the physicality of his condition. But the effort to tell 'a long-term, linear narrative, moving from the disease's origins to its end' (226) is fraught with challenges. A common element in illness life-writing, Taylor's account begins with a chapter entitled 'a diagnosis'. Yet, confrontation with diagnosis does not come as a key moment of change that would suddenly alter his perspective on life (Couser 1997, 82, 64; Jutel and Jutel 2017). For Taylor, there does not seem to be a time before diagnosis, as he 'was only ten years old when [his father] had his nervous breakdown, only fifteen when his disease was diagnosed, only eighteen when he started misidentifying me' (243). That said, understanding Parkinson's disease as a neurological condition helps Taylor rationalize the parent's inability to recognize or remember him (222). 'Parkinson's is a disease of neurotransmitters, of the chemicals which facilitate

communication *between* cells. So I like to believe – whether or not it was neurologically correct – that the brain cells themselves, and the memories they embodied, were still intact. They were just isolated, unable to communicate with one another’ (165, emphasis original). But in the end, he cannot separate the illness from the father as person. His father is ‘*a person* [...] *a whole person* – not just bits and pieces of tremoring hands, distended abdomens, choreiform movements, Lewy bodies’ (253, emphases original; on the impossibility to separate illness from fatherhood, see also Katharina Fürholzer’s essay in this collection).

In a similar way, Taylor’s efforts to learn more about his father’s past remain inconclusive. But, as a contemporary reviewer opined, ‘it is to Taylor’s credit that he fails to pin down his father’ (Laing 2007). To comprehend the father and the relationship with him is much more than learning about his past or defining his pathology. Rather, Taylor comes to the conclusion that the double, which has critically determined his own identity, has been a structuring principle in his father’s life and identity:

My father’s life was so full of these repeated patterns and doubles, I wonder if Capgras syndrome just mixed them up a bit. The pattern of doubles was already there, structuring his life and mind; all Capgras had to do was collapse a few of the pairings into each other [...] Capgras: it’s the end-point of finding patterns and establishing connections: everything collapses into everything else.

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Take Me Home reveals itself as testimony to the importance of relational identity that holds within and beyond a parent’s memory loss and challenging behaviour.

4. Nick Taylor: Conserving family dynamics

A Necessary End (1994) addresses the question of continued self-determination in the face of ageing and illness on account of both parents and children. Nick Taylor faces the fact that ‘anywhere children in the bloom of their lives must confront their parents’ withering. What do our parents need? What must we do

for them? What becomes of us in the process, of our minds and lives and dreams?' (28). Writing after Clare and Jack Taylor's death, Nick Taylor thinks through what really mattered – to him as well as his parents – during the final seven years of their lives. In essence, he traces his parents' shift from third to fourth age (Higgs and Gilleard 2015), from 1984 to 1991. At the same time, *A Necessary End* lets the reader glimpse into a son's coping mechanisms as he seeks to balance feelings of responsibility and the wish for freedom (and relief from responsibility), as he beholds his parents' increasing vulnerability, when they 'grasped the life I would have denied them in the interest of my own convenience' (14). Put differently, *A Necessary End* thinks through the consequences of what Michele Farina advocates in the voice of Atul Gawande: older people living their 'waning days' in a self-determined way (Gawande 2015, 9). And read against Jonathan Taylor's search for his own identity in confrontation with an ill father, Nick Taylor's 'helplessness and confusion' (31) suggest that a son may well experience a challenge to his identity in the face of his parents' ageing, even though he can take comfort from many happy memories of their lived past.

What matters most to Clare and Jack Taylor is their continued autonomy and independence, powerfully conveyed in their decision to move, in their mid-seventies, from Waynesville, North Carolina, to Chapala near Guadalajara in Mexico where they wish to spend their final years. As his parents leave their sheltered housing, under the 'unforgiving eyes of prisoners watching an escape' (8), Nick Taylor admits that it 'would have been much easier on me if, like the others, they had chosen to simply sit and wait for death' (9). But he also knows that the 'ingredients of dignity were all [his father] asked', that all he 'wanted was to meet his basic needs, health among them, and to have some money in his pocket' (76). As the son 'feared for the integrity of [his] own life' (30), what are his coping mechanisms?

Nick Taylor clearly recognizes that his parents continue to be in better health when comparing to some of their friends. Reference to these friends is scattered throughout the memoir as if the author-narrator had to keep reminding himself of his parents' successful ageing. There is the wife of a good friend of his parents, 'in a nursing home with Alzheimer's disease, [who] had forgotten who [her husband] was' (15); there are the parents of one of Taylor's friends, the mother suffering from Alzheimer's, the father, after 'a paralyzing

stroke [...] in a nursing home' (32) for eight years, the last three "unresponsive", a gray and neutral word for living death' (186). Dementia, more than any other degenerative condition, significantly increases dependency and the need for institutional care (Higgs and Gilleard 2015, 50). In linking mental decline to lack of success in ageing (Zimmermann 2020, 98), these cursory observations have a twofold effect. They bring out the momentarily still better health of Clare and Jack Taylor, and they painfully offset what Nick Taylor has been afraid of all along: the loss of his parents' self-sufficiency.

A Necessary End is about what Nick Taylor terms 'generational switch', as '[his] concerns were [those of his parents], twenty years removed' (10).⁶ The memoir's longest chapter, encompassing most of the book's second half, explores in excruciating detail 'my mother's confusion and Dad's dependence' (126) during the year 1989. Previously, in 1986, Nick Taylor could still ignore 'the quirks that started appearing in [my mother's] letters [...] the wrong month, or the wrong year, at the top of the page' (45). During 1989, he describes himself as 'more conscious of their frailty' (136). The pace of the narrative slows down to moment-in-time recordings of conversational exchange. And, reminiscent of Jonathan Taylor's need to chronicle to get a hold on his father's disease, the chapter is scattered with dates and timelines, as if it helped the author-narrator to rationalize his parents' rapid change that 'was all about sadness and memory and loss and struggle and yearning' (121). Such narrative choices signal Nick Taylor's increasing acceptance of his parents' dying, as also suggested by the illustration heading the chapter. Each chapter is introduced by one of Jack Taylor's wood-block prints. But especially the ones heading this and the final two chapters trace the parents' slowing down: 1989 opens with a closed garden gate, followed by 1990 displaying a capsized ship that anticipates Jack Taylor's looking 'like some ghost ship' (163), and the final chapter, 1991, beginning with a church engraving to mark his parents' death.

Two events in the book's narrative and textual centre stand out in 1989: Jack Taylor is in need of a pacemaker; and, after episodes of memory loss and confusion, Clare Taylor has several strokes. These events force Nick Taylor to consider long-term care options, trying to avoid 'someplace sad with stale odors' (103) where his parents would have to follow 'regimented, anonymous

⁶ 'Nick Taylor's Books', accessed 16 September 2020, <http://www.nicktayloronline.com/works.htm>.

routines' that cut them off from everything that had mattered to them (Gawande 2015, 9). More telling than these physical markers is Nick Taylor's discovery of a box with his mother's memorabilia. These include photos that show her 'as an ingenue [sic], full of life and promise, then as a career girl, then as a young wife, then as a working mother' (92). The reader appreciates how strongly Nick Taylor senses his parents' imminent loss around this time when the box of memorabilia is lost – just when his mother's forgetfulness becomes increasingly pronounced.⁷

As in Jonathan Taylor's case, the parent's continued cognitive capabilities condition the son's perception of himself: 'She had no memory for the immediate past, but by reaching back she resurrected my own memories' (167). In reverse, her increasing dementia destabilizes his self-confidence (Burke 2014). Nick Taylor is keenly driven by his publishing activities, including his growing reputation as a non-fiction writer. But his successes are no longer in the parents' awareness, as especially his mother is no longer able critically to appraise his writing. Taylor's own view of himself falters in confrontation with the mother's loss: 'I wanted her to have, if only for a moment, the authority I'd seen that afternoon when I was looking through her papers' (95). That said, Clare Taylor's desire for self-determination remains unbroken until the very end. Nick Taylor observes his mother's struggles to follow physiotherapeutic interventions after her stroke when she finally exclaims: 'Why don't they just let me die!' (170). It takes her son a little longer to appreciate that he has to let go, as 'this was not my mother. This was not the woman she had been, nor the woman she would have wanted to be' (177).

A Necessary End is the story of dying as part of ageing. Death, the knowledge that death will come, dominates the account conceptually – most obviously driven by its chronology. Like the other memoirs explored in this chapter, *A Necessary End*, albeit indirectly in this case, pays tribute to Philip Roth's *Patrimony*. Roth's book about his father's dying of a brain tumour offers a 'mythic version of how to negotiate the death of a parent', while also telling the unadorned truth of the pain and physicality of dying (Hawkins 1999, 118–19). Nick Taylor's account achieves a similar split between myth and reality, perhaps

⁷ Blake Morrison similarly hoped that regaining some of his father's medical equipment 'might restore some part of my father to me' (160).

because it is a story of living in ageing and living in dying, and of the pain that comes from letting your parents live the life they want, until the very end. 'Death itself was not the problem', explains Nick Taylor, 'It was my parents' dotage that I feared. I feared their faltering, their decline, and, finally, their dependence' (27). The way they chose to live eventually determines their difficult end – the image of the bird as a symbol of freedom tracing this shift. Nick Taylor describes them as 'bedraggled birds on their last migration' (111) when they eventually pack up to leave Guadalajara for Fort Myers in Florida to be closer to him and in a more protected environment. He soon sees 'little pieces [...] fly away' (130) and traces his mother's decline through her series of strokes, her arm 'a broken wing to wave' (144). And his father's breathing, near the end 'was weaker, a flutter of a bird's wing' (189).

Still, Nick Taylor's account is mapped on the preferred plot of the redemptive ending, as the younger generation is 'so relieved to be alive' (193). Obviously, Nick Taylor observes his parents' memory in his writing. The first edition of *A Necessary End* has the elegant finish of a precious book to be cherished; it is bound in part linen, has a colour-matching head and tail band, and artistic front cut. In addition, it gives space to the father's 'delicate wood-block prints' which Nick Taylor 'considered his true calling' (3). Above all, the son conveys the parents' immortality in his own existence: 'I have my father's prints and tools and the childhood memories I asked them both to write. I have memories. Most of all, I have myself. Me. I am what my parents made and left. I am what I have to remember them by. And I am the person that they made. I will have to do with that, but all in all, it's not so bad' (193).

5. Conclusion: Masculinity and control

There are demographic as well as political reasons for being attuned to gender when considering carer narratives (Bitenc 2020, 134). Globally, seventy per cent of workers in health and social care are women (Boniol et al. 2019), although there are more and more men who provide care (Arber and Gilbert 1989; Hirst 2001; McDonnell and Ryan 2014; Zimmermann 2017, 26). Such numerical imbalance implies that caring can be seen as challenging hegemonic masculinity. In addition, older men have a lower life-expectancy than women

and are often 'constructed as pre-death' (Hearn 1995, 101). It is perhaps the desire to 'bid for immortality' (Bauman 1992, 51) that, at least partly, motivates men to write about their parents in a way that, compared to adult daughters' writing, is more removed from the caring experience as such (Zimmermann 2017, 23–47).

Michele Farina, Jonathan Taylor and Nick Taylor all write after their parent or parents have died. They are professional writers, two of them active in journalism. They negotiate with the death of those who made them who they are, especially Jonathan Taylor struggling with regret about lost opportunities, as his father 'knew everything (or so it seems to me now) and I talked to him about nothing' (88). The feeling of guilt appears to permeate all three texts (Zimmermann 2017, 129), although Nick Taylor refuses to buy into 'guilt as a condition of living' (194). Blake Morrison, whose account Jonathan Taylor negotiates with, puts this succinctly in a new afterword to his memoir: 'When young, we were impatient with our parents: now we want to atone for our callowness, and to acknowledge what they were and all they did' (231). Read in this light, these authors explore implications for the adult child's identity of the parental generation's memory loss, and, as such, none of them is care-free.

Atonement comes through researching and writing their narratives. In an attempt to explain why the number of female illness narratives is so much higher than those written by men, I had previously suggested that men might find it difficult to maintain a sense of masculinity after having published their account (Zimmermann 2017, 45–6). Where these author-narrators feel compromised by their own feelings they run to the undisputed reference in the field, Roth's *Patrimony*. But their written works are more than atonement. Each of them publishes in tune with their professional aspirations. Farina turns 'pseudo-detective of "dark Alzheimer's"' (337) to scrutinize 'oasis-like care homes and hell-like care homes' (24), Jonathan Taylor writes as the literary critic-cum-author to reflect on the powers and pitfalls of life-writing, and Nick Taylor offers a poetic account of healthy ageing.

All three narratives present the reader with a redemptive ending. Nick Taylor celebrates being alive; Jonathan Taylor is getting married; and Michele Farina pursues his vision of Alzheimer Fest. Each in their own way stays in control of how they share emotions about ageing – their own ageing as much as that of their parents (Specht, Egloff and Schmukle 2013; on the issue of

control, see also the contribution by João Paulo Guimarães and Dae Jung in this collection). Farina stays in control by choosing a particular narrative form. Jonathan Taylor tries to rationalize the effects of Parkinson's with Capgras dementia by approaching it as a biomedical condition. And Nick Taylor accepts his parents' wish for autonomy by placing it alongside his own professional drive. All three make sense of their experience by advocating self-determined ageing in a supportive environment. They write about a mode of ageing that they themselves hope to approach in midlife; a mode of ageing that will ensure they maintain their identity and self.

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